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# A qualitative study to investigate why patients accept or decline a copy of their referral letter from their GP

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## ABSTRACT

### Background

Our practice in Northumberland has offered patients copies of their clinical referral letters for almost 3 years. However, many patients declined this offer and this qualitative study was conducted to determine why almost 80% of patients offered a copy of their referral letter opted not to receive one.

### Aim

To discover why some patients accepted and others declined a copy of the letter written from GP to specialist.

### Design of study

A qualitative focus-group study.

### Setting

General practice in Northumberland.

### Method

Three focus groups of referred patients were created, and discussions were taped, transcribed and analysed for major themes.

### Results

The patients chose to accept or decline a copy of their referral letter for diverse reasons. However, most felt that the ability to choose for themselves whether to have a copy or not was essential.

### Conclusions

The concept of trust in their GP was a major theme that patients related was often behind their decision to decline a copy of their letter. These results, if transferable, may have implications for the application of this policy.

### Key words

choice; correspondence; decision making; referral and consultation; trust.

## INTRODUCTION

The *NHS Plan* for England states that:

*'Patients will receive copies of clinical correspondence written about them as of right.'*<sup>1</sup>

Since 2001 our health centre in Northumberland has offered patients the opportunity to receive a copy of their referral letter. During a 6-month period in 2003 21% of patients accepted the offer of a copy of their letter and 79% declined. This finding was very much at odds with published data, where the uptake was over 90%.<sup>2</sup> A research group was formed to examine why some patients accept and others decline to receive a copy of the referral letter from GP to consultant, and to ascertain whether there were any specific reasons why our practice results were so different from the published research.

## METHOD

Three focus groups were held and all patients who had been referred in the previous 12-month period (2002–2003), were invited to attend to discuss their referral letter. In total 150 patients were approached and 44 agreed to attend the focus groups. One focus group was comprised of patients who had accepted a copy of the letter, one with those who

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had declined a copy of the letter and a mixed group comprising some who had accepted and some who had declined.

Question areas included initial thoughts on being offered a copy of the letter, reasons for accepting or declining a letter, concerns about understanding the contents of the letter, being able to read the letter, whether the letter raised anxiety, or circumstances that might make the letter useful (for example, when someone has a carer, complicated treatments or language difficulties).

The three focus groups were moderated by two members of the research team. Each lasted approximately 1 hour and groups took place in the practice after surgery hours. A grounded theory approach was used to generate themes about the factors influencing the decision to undertake research.<sup>3</sup> This inductive approach is suited to exploratory research since the aim of the research was to understand the views of patients on referral letters without imposing pre-existing expectations, rather than testing hypotheses.<sup>4</sup> Information from this stage of the current study will inform a questionnaire study.

The focus group interviews were taped, transcribed and studied, drawing out common themes and patterns. Using this approach data collection and analysis proceeded simultaneously with themes identified from earlier focus groups informing and subsequently tested out with other participants. Matrix coding frames<sup>5</sup> were constructed for the study for two positions of accepting and declining a copy of the referral letter. Three researchers independently analysed the transcripts to check appropriateness of categories. They then met to suggest other relevant themes or categories, discuss the rationale for introducing new topic areas and to determine that saturation had been reached.

## RESULTS

### *Reasons for accepting a copy of the referral letter*

Themes that emerged from those who accepted a copy of their referral letter were grouped into the following categories: being involved, having control, being satisfied with the service and transparent service.

*Being involved.* This idea was very important to these patients:

*'I would want to see it [the referral letter] and know as much as possible.'*

Some patients found the letter useful as an aide-

## *How this fits in*

Patients at this practice welcomed the idea of being offered the chance to have a copy of their referral letter from GP to consultant. The majority declined the offer as they felt sufficiently well informed about the referral. Those who accepted the copy found it useful and non-threatening.

memoire and that it helped to have the letter as a comparator to the verbal communication in the consultation:

*'To check on what you think the problem was the same as what the doctor thinks is the problem.'*

*'You have time to read it and I think to go back through it.'*

Some felt that continuity of care was important. At the time of referral both the doctor and patient know what has happened from a historical view. However, after referral only the patient can interpret the progress of the problem. The patient in possession of a letter is the only person capable of completing the medical history:

*'The other thing is if you've got a long gap between referral and the time you see your specialist, things may have changed and he may not know that ... I feel that when I get to the hospital that I should like to say, "well actually since the doctor referred me this and this has happened", so I like to fill in [the gaps].'*

The letter can also be a tool to assist patients' understanding, enabling them to take a more active role in their treatment.

*Having control.* A recurring theme was the element of choice that patients felt they should have when considering their referral letter:

*'I think if there is anything written about you, you should have the choice to see a copy of that whether it's medical or otherwise, if somebody writes an opinion or something about you, you should be able to see it if you wish to.'*

This was often linked to the idea of feelings of greater control in the referral process and ultimately the feelings of greater control of their lives:

*'I think it's much more about you and you*

*having a say in yourself now, and I think that can never be a bad thing when you have control over yourself and what you want and what you don't want.'*

In conjunction with the idea of control and wanting to know what was happening was the concept of greater knowledge increasing the patient's confidence in their doctor and the referral process. One participant commented:

*'The more information I have the less anxious I am.'*

By electing to have a copy of their referral letter they felt more reassured and less worried.

*Being satisfied with the service.* Patients felt that by accepting a copy of the letter they were receiving a service that was both accountable and accurate. Accountability was mentioned by several participants as a positive element of the process that they felt was desirable:

*'The doctor has to stand up and be counted and has got to put it down on paper then ... it does bring some accountability on the doctor's behalf. That can only be to the patient's benefit.'*

*Transparent service.* For some patients they simply wanted proof of referral. One participant commented:

*'I think it's vital, to know that things are starting to move.'*

They felt that they were entitled to information and that this transparency was beneficial:

*'I think any openness enhances trust, I mean there is nothing to hide is there. Why can't ... if you are going to have trust between you and your doctor he has got to be absolutely honest with you and doing the best for you as his patient, anything less is not acceptable.'*

### **Reasons for declining a copy of the referral letter**

The reasons focus group participants gave for declining a copy of their referral letter were grouped into the following categories: patient factors, GP relationship factors and referral system factors.

*Patient factors.* The patients who declined a copy of their referral letter often acknowledged a level of lack of interest in the process of referral. They

mentioned the complexity or seriousness of the issue as being central to this idea:

*'It depends on the circumstances, it depends what you are going for, at the end of the day it's no big deal, but I would decide for myself the urgency of it depending on what was wrong with me.'*

They also declined to receive a copy of the referral letter because they often felt that they had sufficient information and did not need more detail concerning the current medical situation.

Several patients mentioned that they considered the letter to be unimportant to them personally. One patient mentioned being too ill, they just wanted an appointment and that was the most important thing. Even though these patients had declined a copy of the letter, many wanted the choice of whether or not to receive it.

*GP relationship factors.* There was no difference between the two GPs in the practice in the number of patients accepting or declining a letter.

The most frequently mentioned feature was that of trust, but also cited were thoughts concerning confidence and the doctor-patient relationship. Patients expressed a trust both in the doctor's judgement and reliability to execute the referral process:

*'I declined because I think there is something to do with trust in your doctor. If you have a doctor in whom you have trust then you do rely on them to convey exactly what you're saying in any letters to any consultant for any referral. I had trust that that was going to happen.'*

The role of a well-functioning doctor-patient relationship seemed pivotal to many patients as part of this confidence and trust. They mentioned clear information passed from doctor to patient as part of this process:

*'I think this is what happens in this practice though, the GPs are very good aren't they? They explain. I just didn't want a letter, I was told and I understood what was being told.'*

Only one person thought that they might not understand the letter. This was not a general view and most people thought that in recent years communication had improved:

*'I do think many years ago it was your body but you didn't really talk about medical terms. That's*

*right and a lot of it went over your head.'*

**Referral system factors.** These factors relate to the perceptions of patients concerning the referral system. Their previous experience of the NHS may explain some of the attitudes behind these quotes:

*'It slows the process down doesn't it?'*

*'It's just creating work for other people, so why bother?'*

*'I wouldn't want to clog up the system ... I think it would too.'*

However, some had thoughts that the referral letter was of lesser importance to them and to the consultant, and for that reason was superfluous:

*'Whenever I've been referred the first thing they do is start from the beginning again and ask everything again, which is understandable ... so basically the letter that goes from here is just a kick-off point, it's only to say to a specialist "this person in my view has got this area of a problem. You sort it. You work out what it is".'*

## DISCUSSION

### Summary of main findings

Copying clinical letters to patients is currently considered 'good practice'.<sup>6</sup> A previous study looked at patient's satisfaction with the idea of having a copy of their GP referral letter,<sup>2</sup> however there have been no studies focusing on the area of consent regarding referral letters.<sup>7</sup>

Much concern has been raised in the medical press<sup>8</sup> regarding the workload attached to this process and the usefulness of such letters. Nevertheless, no studies have asked patients whether they want a copy of such letters. This study sets out to determine why some patients accept and others decline a copy of their referral letter. In this practice 80% of patients declined the offer of a letter because they stated that they trusted their GP, had sufficient knowledge or regarded the problem to be sufficiently trivial not to get involved. They also had concerns regarding the speed of the process if they ask for a copy of their letter. Those who accepted a letter wanted more knowledge of the process and had a feeling of greater control and involvement. They also felt that having a copy of the referral letter gave them greater transparency and satisfaction from the primary care service.

### Strengths and limitations of this study

We feel that this study was conducted rigorously and

that using these qualitative methods our conclusions are valid. This study looks at the important issue of consent in this area for the first time. The study benefited from taking place in a practice with a stable population. We also feel that this research provides important new and timely information. However, as this is a small, stable rural community the findings may not be transferable to the whole country. Further work is necessary to fully inform evidence-based policy making in this area.

### Comparison with existing literature

This study is at odds with the only existing literature in this field. The previous study found an almost universal uptake by patients when offered a copy of their referral letter.<sup>2</sup>

### Implications for clinical practice

These findings may be of interest to clinicians involved in deciding what is best practice in their own setting. If transferable nationwide, it may be that many fewer patients will actively choose to have a copy of their letter from GP to consultant. Many patients will decline a copy of their referral letter if they trust their doctor and feel fully informed. We have found this to be the case at our rural practice.

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### Ethics committee

This study was approved by the Northumberland Local Research Ethics Committee (NLREC14/2003)

### Competing interests

None

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